



Testimony Submitted February 17, 2016

Dear Senator Crisco, Representative Megna and honorable members of the Insurance & Real Estate Committee,

My name is Liela D'Agostino and I am a registered nurse and mother of an eight year son with PANDAS in support of SB 37.

My son, a shining light has fallen victim to a disorder that takes away the innocents of childhood, affects the entire family unit, has had an extreme financial impact and taken an emotional toll on all members of our family. PANDAS has caused both motor and vocal tics, hyperactivity, sensory issues, systemic inflammation, migraines, OCD behaviors, anxiety and even changes in our sons handwriting when he is in a flare caused by exposure to a strep infection.

With the current state of insurance companies not recognizing and supporting coverage for PANDAS our son was shuffled around from specialist to specialist (neurologist, rheumatologist, ADHD specialist, psychologist etc) None of these specialist were able to manage and treat our sons symptoms. They did try within their specialty box and the result was he was put on numerous different psychiatric and ADHD medications that did not help. They actually exacerbated his symptoms. His tics and behaviors worsened to the point the he had to wear protective clothing to prevent self injury and had to learn at six and seven years old to explain to his peers that what they were seeing were things that were out of his control. All these medications that were covered by insurance were making my son worse, not better. We fought for coverage, but didn't get it so we scraped pennies for the health of our son and our entire family unit.

Paying out of pocket of the right specialist who understands and knows how to treat PANDAS was what we had to do. Within weeks, not months or years, but weeks we saw our son change...we saw our whole family dynamic change. We were lucky that we were able to find a way (although not easy) to get the best help possible for our child. However, there are many that simply can't find the means to pay for the right treatment for PANDAS.

So what is the real expense? Wrong diagnosis and failure to cover the right diagnosis results in kids taking medications that have extreme side effects (sometimes requiring other medications to counteract the negative effects of the original medication), cost to insurance companies to pay for these medications, numerous wrong specialist seen, our children being robbed of their innocents/childhood and lasting/escalating medical ailments because of improper treatment or delayed treatment resulting in long term negative effects for our children and higher expenses for the insurance companies.

Coverage for children with PANDAS is a win-win for our child and the insurance companies. Treat the cause and healing our children will equal lower overall costs to the insurance companies.

Liela D'Agostino

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